

**Maryland Cancer Control Plan
Town Hall Meeting
Bon Secours Baltimore Health System
Liberty Village, West Pavilion
Thursday, August 1, 2002**

The fifth Maryland Cancer Control Plan Town Meeting was held at the Bon Secours Baltimore Health System, Liberty Village, West Pavilion on August 1, 2002, from 6:00 to 8:00 p.m. Thirty persons attended the meeting. Robert Villanueva, MPA, Executive Director of the Maryland State Council on Cancer Control (the Council), opened the meeting. Mr. Villanueva stated that The Council reviews the needs of the community in relation to cancer and advises the legislature on relevant policy. The Council is providing oversight to the development of a new cancer control plan to be published next year. There are 15 sub-committees and over 300 persons participating in this process. The goal of the Council at this meeting is to gain knowledge of the issues related to cancer control in the Baltimore region. He asked that participants be frank and open about the topics addressed.

Mr. Villanueva also provided an introduction to the town meeting concept, explaining that it is a way to keep the community involved. He indicated that the comments will go directly to the appropriate committee and will be used as the basis for the cancer control plan. He encouraged the participants to return in the spring for the follow-up meetings and indicated that the list of participants from today's meeting would be kept and used as a mailing list in the future.

Mr. Villanueva then introduced the panel members: Donna Cox, M.Ed, Co-Chair, Prostate Cancer Committee, State Council on Cancer Control; Albert L. Blumberg, M.D., State Council on Cancer Control, Elaine Carter, American Cancer Society; and Marsha Bienia, MBA, Core Planning Team, who would respond to questions or might ask for more information.

Participants were asked to follow the Speaker Guidelines (Attachment I) provided to all attendees. Speakers were asked to:

- a. Limit remarks to 5 minutes
- b. Respond to the 3 questions listed on the Speakers Guide, and/or
- c. Relate comments to the 15 formal committee topics (Attachment II)

It was noted that additional comments or concerns could be mailed or e-mailed to Virginia Thomas at UMBC (contact information listed on the Speakers Guide).

SPEAKERS

Mary Ann Bachmann

Union Memorial Hospital Oncology Center

Most important issues to address include transportation, nursing/health assistance to provide in home support and care, pain management, and availability of in-home equipment.

Currently there is a shortage of in-home health care nurses.

Concerned about the length of time it takes for a breast cancer patient to be seen by a counselor after surgery. After surgery, patients need advice, support, and equipment as soon as possible.

Elaine Carter

Panel Member

Do clients use the Reach For Recovery Program? Reach For Recovery should be seeing the patient within 24 hours of the referral and quickly get whatever they need after that first visit.

Donna Cox

Panel Member

This is critical information for the Patient Issues Committee and we will see that they hear it.

Marie Gray-Brown

Union Memorial Hospital Community Representative

Concerned how young women are treated when they are diagnosed with breast cancer.

Union Memorial is planning to find out how women younger than 40 are being treated and what exactly they need that is different from the older patient.

Marsha Bienia

Panel Member

Department of Health and Mental Hygiene has a breast and cervical cancer program for low-income women who have no insurance or are not eligible for Medicaid. If they are diagnosed with either type of cancer, have them call the office. They will be given an intake interview. If they qualify, they can get treatment, medications, equipment, and hospital care. It will all be paid. The program was created to fill the gap for persons with no insurance and not eligible for Medicaid.

Josafina Pizam

Cancer Survivor and member of the Patient Issues Committee

Speaking today for the members of the Wellness Community, other survivors and for Hope Ziegler, who recently died from breast cancer.

Cancer transforms one's entire life. Even the new psychosocial model still does not meet all the needs of a patient.

Trying to get the help hinders the healing.

Many patients cannot continue to work after their diagnosis and during and after treatment. However, there is no occupational support for retraining. For example, Hope Ziegler could not work as massage therapist due to her cancer. Her will to live was impacted

by not being able to work. She had to learn from other patients that she could have been helped.

Recruit more cancer patients to participate in the planning process and the ongoing oversight of the Cancer Plan.

The clients want a better partnership. Patients want to be recognized and heard directly. We do not want to be spoken for but included.

Ann Mulligan

Cancer Survivor since 1993

Representing all cancer survivors

Education is critical. We must know the resources and how to find them.

Some resources are not known until it is too late to be of assistance.

The Wellness Community is an example of an organization that gives all it can to each person.

Transportation is as vital for surviving as the treatment and support. Recently, I met a woman at the Wellness Community who had cancer and who did not drive. She came on the light rail and was asking for a ride back to the train.

Hearing about resources is not enough. All cancer patients need to know where and how to access them.

Sensitize doctors so that they tell the patient what is available to meet their special needs and where to find it.

Patients need help with learning about and obtaining medications but currently only the Wellness Community is providing that information. For instance, many drug companies will give free medications to patients but no one tells the patients how to contact those companies.

Maxine Saunders

Cancer survivor – Diagnosed with lung cancer in 2000

The Wellness Community services all are free (e.g., yoga, Ti Chi, meditation).

As a survivor, I reached out for help and received it from the Wellness Community. The Cancer Plan must support the Wellness Community.

People need to realize that life can be livable with cancer.

I volunteered for the Lung Cancer Committee, but as of now no meetings have been scheduled.

As a volunteer for the Wellness Community, I share my story with other lung cancer patients and offer them encouragement and support.

Nurses and doctors are so overworked that they do not have time to learn all the resources.

The Wellness Community can assist them to know the resources and then to tell their patients about them.

A good example is Smith Farm. This is a place for patients to get away from it all for a week. The activities include information on diet, massage, support therapy, group discussions, and other programs. It made a tremendous difference for me. It cost \$1,100 dollars. My sister paid half for me but others are not so fortunate.

Transportation is so important. We get calls to the Wellness Community from people who are interested in coming to programs but cannot because they have no transportation.

The Cancer Society does have a volunteer transportation program, but it is limited.

Many people who call do not even know what the cancer diagnosis means, what will happen to them, what they can do to have a better chance at survival, or what will happen as part of the treatment.

Elaine Carter

The American Cancer Society has an information number (888-227-6333). Trained counselors are there every day to assist patients.

The Cancer Society would like to receive feedback on the service.

Donna Cox

Has the Lung Cancer Committee met yet?

Robert Villanueva

That committee is being currently being formed and we will be contacting members very soon.

Pauline Bloise-Taylor

Associated Black Charities of Central Maryland

Want to provide information on MOTA. This group is working with minority community organizations to educate and support people in the community with cancer.

Language is a major barrier to education. The information is not in a language that they can read.

Providers are not culturally sensitivity to the patients' needs.

There is fear from the members of the undocumented community that there is a link between the provider and immigration services. So, the undocumented will not seek services.

People do not know what to expect from a screening or what to expect if follow up is needed.

Donna Cox

The Patient Issues Committee is recommending that education be provided on what occurs during the screening, what will happen if there is a diagnosis, and if there is no cancer diagnosed, how long to wait until another screen should be done.

Irma Reeder

ANGELS Project

This project is composed of low-income women who are called angels. They have been trained to be community educators and work in their own communities.

Need to increase awareness in the African-American communities regarding screening, cancer signs and symptoms, resources, and treatment.

Russell Stewart

Representing Senator Clarence W. Blount

Our office is being told people cannot access services because they owe the system money.

Donna Cox

Breast, cervical, and prostate screenings are being funded through the tobacco settlement money and are not connected to what a person may owe the health system. No one should be refused as long as the money is there.

Russell Stewart

Johns Hopkins Hospital's name is coming up to us again and again as not screening a person if the client owes them money.

Are you saying there are no eligibility criteria?

Donna Cox

There are eligibility criteria, but because of the high rate of prostate cancer in African American men, we will screen any African American man over 45. If they have no insurance, then there is no cost. If they have insurance, the funding pays for whatever the insurance does not pay. Basically it is free for African American men age 45 or over. There is outreach to get both men and women into the screenings. If what you are telling us is the case, it needs to be taken to the appropriate persons.

Russell Stewart

Also, people are being turned off by the number and type of questions asked in order to receive the screening.

Donna Cox

There are forms that must be filled out. As screeners we must respond to the funder regarding what we are doing. We must comply with regulations. There is a report done for the legislators and they want the information on what is happening. If we want to be refunded we must comply.

Irma Reeder

How the questions are asked make a big difference in how people respond to the questions. Sensitivity training for the screeners would not hurt.

Fund community based projects that do have an awareness of how to communicate in that particular area.

Need to look at pain management in the nursing homes. A new physician does not know the patient and may discontinue or change a medication that was controlling pain. In some cases, this is just to save money.

Need to train and monitor nursing homes regarding pain management treatment.

Pearl Lewis

**Health Advocate/ Founder, Maryland Patient Advocacy Group
National Kidney Foundation, Crohn's and Colitis Foundation, Baltimore Ostomy Association**

Many chronic illnesses predispose the patient to cancer and have not been included in the Cancer Control Plans in the past.

Many patients especially those awaiting stem cell transplants are on immunosuppressive drugs but are not given information that it may predispose them to cancer.

Barriers

People lack awareness of the threat of cancer.

Specialists treat one diagnosis, one disease, or disorder and do not monitor the other organs that can be affected.

Cancer prevention, screening, and treatment do not exist for these patients.

Fiscal realities sometimes interfere with a patient receiving prevention, education, screening, and treatment. For example, patients frequently move in and out of the eligibility for Medicaid and then lose their services.

Suggestions

Invite members of non-profit health community to participate in the planning process.

Create brochures on cancer for all patients that have a disease that predisposes them to a certain type of cancer. Include information on prevention.

Ask churches and synagogues to reach out to their communities.

Teach doctors that they must communicate, listen, and understand what the patient is saying.

The issue is control of the situation, and you only have control when you have knowledge.

Russell Stewart

Expressed concerns regarding the quality control and oversight of last two Cancer Control Plans.

Transportation must be made available now. People cannot get to care.

Home equipment and other needs after surgery must be provided.

Pleased with the planning process but want to be sure that all the issues are addressed.

Want the summary from the previous two plans to be made available for review.

Need to see what is really happening, compared to what was stated in the Plan.

Decrease the number of questions a person has to answer before they get care.

I understand that additional money has been assigned. How will that additional money will used?

Surina Aquilar

University of Maryland Statewide Health Network

Works in a community outreach program funded by the tobacco settlement money. There are many resources that would help patients.

Target the seven cancers and other diseases caused by tobacco and tobacco products.

Baltimore City residents are less apt to reach out because they have more pressing issues to deal with, like food and lodging.

They are not concerned about cancer until it is too late.

Need to step in and address the other barriers as well as the potential cancers.

Lori Russell

**Director of Disease Management and Case Management
Johns Hopkins Healthcare**

Think statewide since the issues differ in each area of the state.
Hopkins is creating an end-of-life care program.

Marsha Bienia

Meetings are being held through out the state on a regional basis.
There are differences being heard in each meeting.

Rebecca Burrett

Outreach, Chase Brexton Health Services

We see all persons regardless of income at Chase Brexton.
Collaboration is critical and we work with all organizations.
We do PAP tests and other screenings. Many times outreach and just taking the time to listen makes a difference in a client's response. Ten percent of our clients are now going regularly for screenings.
Chase Brexton has been successful since we are part of the community.
Prevention is critical but people need to know that the screener is interested and will talk with them
Go to the places where the people are.
Include in the definition of underserved the sexual minorities (Gay, lesbian, transsexual).
Sexual minorities go for service or screenings and are told by the provider that they do not belong at the screening.

Rosemary Noble

Baltimore County Health Department

The tobacco restitution money funds breast, cervical, and colorectal cancer programs.
Want people to know that we exist and that we will go out of the way to get the patient to the screening and then to provide any service needed. Transportation is included.

Dr. Caswell Evans

Resident of Montgomery County

Former Health Officer in Los Angeles

Past president of the Public Health Association

Oral cancer rates in Maryland are higher than national level.
In the African-American population, the rate is the highest and that might be linked to tobacco and alcohol use.
Oral cancer can be treated and diagnosed early if exams are done routinely.
There is no invasive procedure but few physicians know how to do the exam or if they do know, they do not know what to look for.
Dentists do not even do routine screenings.
Increase the expectation of clients that they should have an oral exam as part of a physical or a dental visit.
Access to care for diagnosis and treatment is critical.

Insurance does not cover oral screens nor does Medicaid or Medicare. This must be changed.

Accurate data on oral cancer must be obtained.

Increase detection and prevention by having licensed persons learn how to do the screening.

Gretchen Derewicz

American Cancer Society

There is a volunteer driver service in the Cancer Society.

We want to make people aware of what the Cancer Society does. We improve the quality of life for cancer patients by getting them resources and information.

Partnerships we have are varied and we want to form more.

The Cancer Society can identify resources that are needed and can field questions for groups that are not able to do it for themselves.

1-800- ACS-2345 is always there. You reach an individual who will get you to a professional as soon as possible. Materials are sent within two to three days and there is no charge.

Urged audience to call on Cancer Society to support community programs.

Dr. Blumberg

Panel Member

Are there any other comments?

Audience

Work on behalf of the persons who do not qualify for programs.

Cover all men in the city for prostate screening.

Provide screening and care even if the patient has no insurance, does not qualify, or is undocumented.

Survivor

Need to clarify if we, as a non-profit, can speak here or if this is considered lobbying?

Robert Villanueva

There is no legislation being considered here, so it would not be lobbying.

Marsha Bienia

This is an educational opportunity for us to hear what issues and suggestions you would like to have us address in the plan.

Dr. Albert Blumberg

Speaking as a private citizen

There is no guarantee that the cigarette restitution funds will continue as they are now.

Ask the candidates to continue the Cigarette Restitution Fund and to fund it at a higher level.

The fifty million is not a set figure. The decision is made every year on how to spend the money.

The General Assembly has to hear that we need the money.

LaVeda DeVone

**Community Specialist, East Baltimore
American Cancer Society**

There are programs that people do not know about.

Mandate the registration of all programs in the state and create a directory of services.

Audience

People do not know that programs exist. Create a state website.

BGE has a purple book with all resources. We need a similar book for the people with cancer and who do not have access to websites.

Have a website for providers to get the information so that they can then share it with their patients.

Do not forget the transportation concerns.

Need funding for transportation. Volunteers have liability issues.

Russell Stewart

Consider using the public shuttle buses that come to many neighborhoods at request of seniors. Give vouchers to the patients.

Use the services that exist but use them better.

Audience

The shuttle system has multiple problems and cannot be depended on for a scheduled appointment.

Does the Cancer Council make recommendations on the cigarette restitution funding?

Marsha Bienia

No, we do not. If the money is cut in half, we cannot do what you are asking. Your voice must be heard regarding the money.

Audience

The Wellness Community would like to hear a speaker on the Cigarette Restitution Funding Program.

Consider using hacks (private taxi cabs).

There is a legal concern regarding the hacks, so they cannot be used.

Marsha Bienia

Thank you for coming

We will do our best to reflect your ideas.

Robert Villanueva

There will be a conference on the recommendations on October 16, 2002.

Please attend and give your comments on the recommendations only. We will post the recommendations on the web prior to the conference.

Thank you all for coming this evening.